# Impact of vitiligo on quality of life of patients in Herat, Afghanistan

Abdul Malik Hooshmand, MD <sup>1\*</sup> Nasar Ahmad Shayan, PhD <sup>2</sup>

- Dermatology Department,
   Hooshmand Skin and Cosmetic
   Hospital, Herat, Afghanistan
- Department of Public Health and Infectious Diseases, Faculty of Medicine, Herat University, Herat, Afghanistan

\*Corresponding author: Abdul Malik Hooshmand, MD Consultant and Head of Dermatology Department, Hooshmand Skin and Cosmetic Hospital, Herat, Afghanistan Email: malikhooshmand@yahoo.com **Background:** Vitiligo is a chronic pigmentary disorder of the skin. Although predominantly asymptomatic and not life-threatening, vitiligo may considerably affect patients' quality of life (QoL). It has been suggested that vitiligo patients suffer from low self-esteem and poor body image, which may cause a lower level of QoL. The objective of this study was to evaluate the effect of vitiligo on patients' QoL in Herat, Afghanistan.

**Methods:** This descriptive study was conducted at Hooshmand Skin and Cosmetic Hospital and the associated phototherapy center from November 2015 to April 2017. A total of 170 patients above 16 years of age were recruited. A valid translated Persian version of the Dermatology Life Quality Index (DLQI) was completed by subjects, and data were collected using structured datasheets.

**Result:** On average, patients were  $27.84 \pm 10.74$  years old, and 40.6% were males. The overall mean DLQI score was  $9.72 \pm 5.82$ , including  $9.93 \pm 4.64$  in women and  $9.42 \pm 6.11$  in men. The DLQI score was significantly related to the age, type of disease, treatment history, and employment status. Compared to males', females' QoL was more impaired in feeling (Q2) and type of clothing (Q4) (P = 0.020 and P = 0.021, respectively).

**Conclusion:** Vitiligo patients showed a moderate limitation in their QoL. Hence, the managing team should focus on the QoL and psychosocial well-being of vitiligo patients in addition to their clinical condition.

**Keywords:** vitiligo, quality of life, Afghanistan, dermatology life quality index

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#### INTRODUCTION

Vitiligo is an acquired chronic pigmentary disorder of the skin resulting from the selective destruction of melanocytes. The estimated worldwide prevalence of vitiligo is around 0.5-2%, making it the most common depigmenting disorder <sup>1</sup>. It equally affects all ethnic groups and skin phototypes and appears with equal frequencies in both genders, though women seek consultation more often than men, probably due to the greater negative social impact <sup>1,2</sup>.

The disease usually begins in childhood or young adulthood, with a peak onset at 10-30 years. Two forms of vitiligo are well recognized: segmental and non-segmental. Non- segmental includes the acrofacial, mucosal, generalized, universal, mixed, and rare variants. Generalized vitiligo and acrofacial vitiligo are the most common subtypes <sup>1,3,4</sup>. The etiopathogenesis of vitiligo is not clear, yet several theories have been proposed. Most evidence supports an autoimmune phenomenon associated with an underlying genetic predisposition <sup>3,5,6</sup>.

Vitiligo is often dismissed as a cosmetic problem,

though it can have a devastating psychological effect with a considerable burden on daily life <sup>1</sup>. The disease has a major impact on self-esteem and self-perception. In some societies, vitiligo is poorly understood and is believed to be a sign of leprosy or sexually transmitted disease. Many vitiligo patients are anxious about the disease worsening, have their social life affected, and are embarrassed, depressed, and ashamed <sup>2</sup>. The fact that vitiligo is a chronic disease with an unpredictable course and long-term treatment with lack of uniform response makes it more stressful for the patients <sup>7</sup>. Studies have shown the occurrence of psychiatric morbidities such as depressive disorder, adjustment disorder, and anxiety in up to 25% of vitiligo patients <sup>8,9</sup>.

Quality of life (QoL) is a multidimensional index that considers social, behavioral, and cultural factors. Various tools have been developed for measuring QoL focusing on different diseases. The Dermatology Life Quality Index (DLQI), proposed by Finlay *et al.* in 1994, is the first dermatology-specific QoL instrument <sup>10</sup>. It is a validated questionnaire with 10 simple questions used for more than 40 skin conditions in over 80 countries, available in over 90 languages. More than 40 published studies worldwide describing its use in patients with vitiligo <sup>11,12</sup>. The reliability and validity of the Persian version of the DLQI were approved in Shiraz, Iran <sup>13</sup>.

This study aimed to assess the QoL in vitiligo patients and its relation with different variables in the largest province of the west part of Afghanistan by applying the DLQI.

# PARTICIPANTS AND METHODS

# Study design, place, and duration

This descriptive study was conducted at Hooshmand Skin & Cosmetic Hospital and the associated phototherapy center in Herat, Afghanistan, between November 2015 and April 2017.

#### Sample size and eligibility criteria

A total of 170 confirmed vitiligo patients were included in the study during an eighteen-month interval. The study participants consisted of residents of Herat and patients from other provinces who were

living in Herat during the study period. Patients who were above 16 years of age, were willing to participate in the study, could communicate fluently in Persian, and did not have a history of severe mental disorder were included in the study.

#### **Data collection**

All patients were examined by a dermatologist, who confirmed their diagnosis. Specific forms were designed to collect data on the socio-demographic profile (sex, age, marital status, residential address, and level of education) and disease-related variables (duration of disease, positive family history, history of treatment and its efficacy, and exposed vs. non-exposed areas of involvement). The sites of involvement and clinical type of disease were determined by standard physical examination. Two research assistants (a doctor and a last year medical student) were trained to describe the aim and nature of the study to the participants, obtain their consent, and to fill the forms.

Next, the patients, who provided informed consent, were asked to fill a validated Persian version of the DLQI questionnaire. For illiterate patients, research assistants read and described the questionnaire to them, and filled it according to their response. The Persian version of the DLQI was validated by Aghaei *et al.* in Shiraz Iran and the reliability of the questionnaire was shown by a high Cronbach's alpha coefficient ( $\alpha = 0.77$ ) <sup>13</sup>. Afghanistan (especially the Herat province where this study was conducted) and Iran have a shared history, culture, and, language (Farsi/Persian). Therefore, considering all these points, we used the validated Persian version of the DLQI in our study.

# **DLQI** questionnaire

The DLQI questionnaire includes ten items that assess different aspects of a patient's life in the last week. The questions include "symptoms" (itching, pain, and irritation), "feeling" (embarrassment, distress, and anger), "routine activities" (shopping and house works), "kind of clothes", "social or leisure activities", "sexual activities", "interpersonal relationship" (with wife, friends, relatives), and "treatment" <sup>1,10</sup>.

Each question has four possible answers scored

Dermatology Life Quality Index (DLQI) Score	Interpretation
0–1	No effect at all on patient's life
2-5	Small effect on patient's life
6-10	Moderate effect on patient's life
11-20	Very large effect on patient's life
21-30	Extremely large effect on patient's life

from 0 to 3 (3 = very much, 2 = a lot, 1 = a little, 0 = not at all). The DLQI score is calculated by summing the scores of all questions, resulting in a maximum of 30 and a minimum of 0. The higher the score, the more QoL is impaired. The average time to fill this questionnaire is less than 5 minutes. DLQI score interpretation is done as follows  $^{10,14}$ :

# Statistical analysis

Statistical analysis was performed using IBM SPSS Statistics Version 21.0. Numeric variables were given as mean ± standard deviation (SD), median (1<sup>st</sup> quartile-3<sup>rd</sup> quartile), and minimum and maximum, while categorical variables were given as frequencies and percentages. The chi-squared test was used to observe the difference between two categorical variables, while the Mann-Whitney U test was used for determining the difference between two continuous variables in the absence of normal distribution. For more than two categories of variables, the Kruskal-Wallis test was used.

## **Ethical considerations**

This study was approved by the Research and Ethics Committee, Herat Faculty of Medicine, Herat University, Herat, Afghanistan.

#### RESULTS

A total of 170 patients with vitiligo were included in this study. The participants ranged between 17-75 (mean  $\pm$  SD: 27.84  $\pm$  10.74) years in age, and 69 were male (40.6%). Other demographic data are shown in Table 1.

The duration of the disease ranged from  $\leq 1$  year to  $\geq 12$  years. Generalized vitiligo was the main type of clinical involvement seen among the patients (n = 99, 58.2%), while segmental vitiligo was only found in 12 participants (7.1%) (Table 2).

**Table 1.** Socio-demographic profile of the study's vitiligo patients – Herat, Afghanistan (n = 170)

Socio-demographic variable	n	%		
Sex				
Female	101	59.4		
Male	69	40.6		
Age (Years)				
17- 20	55	32.4		
21- 30	63	37.1		
31-40	29	17.1		
41-50	16	9.3		
≥ 51	7	4.1		
Marital status				
Single	75	44.1		
Married	95	55.9		
Education				
Literate	121	71.2		
İlliterate	49	28.8		
Residence				
Urban	117	68.8		
Rural	53	31.2		
Total	170	100.0		

**Table 2.** Disease-related characteristics of the patients (n = 170)

Characteristics	n	%
Involved sites		
Exposed	37	21.8
Non-exposed	15	8.8
Both	118	69.4
Clinical types		
Acrofacial	16	9.4
Segmental	12	7.1
Generalized (vulgaris)	99	58.2
Focal	43	25.3
Mucous membrane involvement		
Oral mucosa	22	12.9
Genital mucosa	15	8.8
Both	4	2.4
None	129	75.9
Duration (year)		
< 1	14	8.2
1 - 3	47	27.6
3 - 6	47	27.6
6 - 12	36	21.2
> 12	26	15.3
Family history		
Positive	45	26.5
Negative	125	73.5
Treatment		
No treatment	21	12.4
Effective	51	30.0
ineffective	98	57.6
Total	170	100.0

The DLQI scores ranged from 1 to 26 with an overall mean of  $9.72 \pm 5.82$ , indicating a moderate effect on the patients' QoL. The mean score in females was  $9.93 \pm 4.64$  and in males was  $9.42 \pm 6.11$ . There was no effect on the QoL in 3 patients (1.8%), while 7 patients (4.1%) experienced an extremely large impact. Fifty-eight participants (34.1%) had a DLQI score of 10-20, indicating a very large impairment of their QoL (Figure 1).

The highest mean DLQI score was seen in the age group  $\leq$  30 years (10.42  $\pm$  5.98), which was statistically significant (P = 0.026) compared with those > 30 years with a mean score of 8.15  $\pm$  5.15. Moreover, patients with acrofacial vitiligo had the highest mean DLQI score (14.38  $\pm$  6.57). Compared

to focal vitiligo, the QoL was statistically more impaired in acrofacial and generalized vitiligo patients (P<0.001 and P = 0.006, respectively). Similarly, the QoL of employed patients and patients who had experienced non-effective treatments was remarkably more impaired than unemployed patients and patients who had experienced effective treatments (P<0.001 for both) (Table 3).

A marked limitation in QoL was seen in the DLQI question for feelings (Q2) (2.21  $\pm$  0.972). On the other hand, the least effect of vitiligo on QoL was reported for sexual activities (Q9) (0.46  $\pm$  0.83) and exercise (Q7) (mean 0.46  $\pm$  0.88). There were statistically considerable differences between DLQI scores of males and females in different domains.

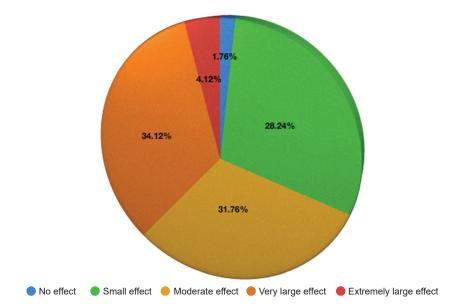


Figure 1. Dermatology Life Quality Index (DLQI) results.

Table 3. Some variables with significant effects on the DLQI of recruited patients

Variable	Category	n	Median	Mean	SD	P-value
Age (Years)	≤ 30	118	9.50	10.42	5.98	0.000*
	> 30	52	7.00	8.15	5.15	- 0.026*
Employment history	Employed	87	14.00	13.37	5.48	40.004*
	Unemployed	83	5.00	5.90	3.07	- <0.001*
Treatment history †	No treatment	21	7.00	9.33	6.39	
	Effective	51	5.00	4.75	1.82	<0.001**
	Ineffective	98	12.00	12.40	5.34	_
Clinical type ‡	Acrofacial	16	14.00	14.38	6.57	
	Segmental	12	6.50	8.50	5.46	
	Vulgaris	99	10.00	10.35	5.83	- <0.001**
	Focal	43	6.00	6.88	3.98	_

<sup>\*</sup>Mann-Whitney U test

<sup>\*\*</sup>Kruskal-Wallis test

<sup>†</sup>Effective-no treatment (P = 0.003); effective-ineffective (P < 0.001); no treatment-ineffective (P = 0.048)

<sup>‡</sup>Focal-vulgaris (P = 0.006); focal-acrofacial (P < 0.001)

Table 4. Comparison of different Dermatology Life Quality Index (DLQI) domains between males and females

Domain	Female	Female (n=101)		Male (n=69)	
	Mean	SD	Mean	SD	– <i>P</i> -value*
Symptoms	0.74	0.91	0.54	0.76	0.164
Feelings	2.35	0.90	2.00	1.04	0.020
Daily activities	1.08	1.14	1.01	1.12	0.729
Type of clothing	1.33	1.18	0.90	0.99	0.021
Social and leisure activities	1.13	1.04	1.22	0.98	0.520
Sport (exercise)	0.28	0.71	0.72	1.03	0.001
Working or studying	0.99	1.30	1.01	1.35	0.961
Interpersonal relations	0.74	0.97	0.77	0.91	0.665
Sexual difficulties	0.49	0.88	0.42	0.76	0.835
Treatment related problems	0.81	0.92	0.81	0.83	0.776
Total Score	9.93	5.64	9.42	6.11	0.468

<sup>\*</sup>Mann-Whitney U test

The female QoL was more impaired in feelings and types of clothing (P = 0.020 and P = 0.021, respectively), while the males' QoL was more affected in sports activities (P = 0.001) (Table 4). Statistically, there was no relationship between DLQI and the duration of disease, sex, and marital status of the patients.

#### DISCUSSION

The present study showed that vitiligo has a moderate effect on patients' QoL in Herat, Afghanistan. The mean DLQI score in our study was 9.72, which is in the moderate effect range yet close to a very large effect on QoL. This is a high score when compared to most of the other studies. Ingordo et al. found a mean score of 1.82 <sup>15</sup>, Ongenae et al. showed a mean of 4.95 <sup>16</sup>, while Morales et al. and Mashayekhi et al. observed mean scores of 5.2 and 7.54, respectively <sup>17,18</sup>. There are many other studies conducted in different geographic regions with various cultures and skin phototypes and lower mean DLQI scores <sup>13,19-25</sup>. However, to the best of our knowledge, only a few studies found higher mean DLQI scores than our study 26-28.

Whether this high score and impaired QoL are due to cultural beliefs and skin color is not clear, though the skin phototype of our people is not as dark as of Blacks or Indians. A few reasons may explain the high impairment of QoL observed in our study population. Firstly, some Afghans avoid contact with vitiligo patients as they consider vitiligo a contagious or infectious disease, resulting in patients' social isolation. Secondly, there is a

common belief that vitiligo is an inherited disease, which decreases patients' chances to marry, especially for female sufferers. Also, vitiligo patients and their families impose many unnecessary and unproven dietary restrictions, leading to the avoidance of numerous valuable nutrients. Some even believe that vitiligo is a punishment from God as a result of the committed sins. These factors can seriously impair the social and personal life of vitiligo patients.

We observed a higher mean DLQI score in the age group of  $\leq$  30 years compared with those > 30 years of age. Similarly, some studies found higher mean scores in specific age groups <sup>18,27,29,30</sup>. However, other studies did not find any significant correlation between DLQI score and age <sup>13,16,19,24,31</sup>.

We found that employed patients had considerably higher DLQI scores than unemployed ones. This is similar to the finding of Wong *et al.* <sup>22</sup> Kiprono *et al.* observed a comparable result as well <sup>24</sup>. Patients who work go outside and meet other people, which possibly makes them feel embarrassed and adversely affects their QoL.

There was a statistically significant relationship between DLQI and the clinical type of involvement. Patients with acrofacial and generalized involvement showed higher scores and more impaired QoL when compared to focal vitiligo patients. Wong *et al.* found a statistically significant relationship between DLQI and the site of vitiligo; patients showed higher scores on visible sites than covered sites. This is compatible with the findings of Silverberg *et al.* <sup>22,23</sup> Radtke *et al.*, Wang *et al.*, and a few other authors established similar results as well <sup>30-34</sup>. However, other studies did not find any

relationship between QoL and site of involvement or visibility of lesions <sup>16,18,19,24</sup>.

Our study found that patients with unsatisfactory treatment history had significantly more QoL impairment than patients who experienced effective treatment. It is known that long-term treatment and lack of effective therapy is usually upsetting and demoralizing for vitiligo patients <sup>12</sup>. Reham Ezz *et al.* compared the QoL of a group of patients before and after three different methods of grafting and found that there was a statistically significant improvement of QoL in the group with the best treatment result <sup>35</sup>. Comparable findings were presented by Al-Shobaili, Chahar *et al.*, and Holme *et al* <sup>33,34,36</sup>.

In our study, there was no relationship between DLQI scores and gender, which is in agreement with some of the previous studies <sup>7,10,19,20,23,27,37</sup>. However, there are studies that concluded the opposite <sup>18,24,29,30,38</sup>. Moreover, we did not find a significant relationship between the DLQI score and the duration of disease, which is inconsistent with most other studies <sup>7,16,19,22,29,31</sup>, except those of Ghajarzada *et al.* <sup>39</sup> and Parsad *et al.* <sup>27</sup> In this manner, no notable difference was found in DLQI scores between literate and illiterate patients. Dolatshahi *et al.* did not see any relation between the DLQI and educational levels in patients with vitiligo, but Mishra *et al.* observed the contrary <sup>20,31</sup>.

Between the genders, females had more impaired life quality in terms of feelings and types of clothing. However, males' QoL was more disturbed in sports activities. These results are compatible with the findings of Ongenae *et al.* and Al Robaee <sup>16,26</sup>, but not with those of Sawant *et al* <sup>37</sup>.

#### **CONCLUSION**

This study revealed that vitiligo moderately impairs the QoL of the patients. The age of patients, type of clinical involvement, the effect of previous treatment, and employment status could influence this impairment. Dermatologists should pay more attention to vitiligo, which is challenging to treat and has significant negative effects on patients' QoL. It is crucial to recognize and address the psychological and social issues caused by vitiligo, which would result in QoL enhancement and better treatment outcomes.

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